In search of a decision-making framework for involving users who have learning disabilities or sensory impairments in the process of designing future technologies

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Abstract: A comprehensive literature review was undertaken in order to identify design approaches that have been employed with users who have learning disabilities or sensory impairment; the factors that influenced their choices and the extent to which the approaches and techniques adopted were successful. There was a huge variation across the corpus regarding whether a justification was offered for the choice of approach and the extent to which those justifications were supported by evidence. In addition there was a lack of comprehensive evaluation of the design approaches. Technology designers who intend working with users with learning disabilities or sensory impairments therefore currently have little to help them decide which design approach might be the most appropriate or effective.

Keywords: disability, design process, user participation, decision-making

1 Introduction

This paper will present the results of a comprehensive literature review regarding methods for including adults with a diverse range of access preferences frequently associated with the labels of sensory impairment and learning disability in the design of technologies. The objective of this review is to identify if there is any consensus around which design approaches are appropriate and effective to use with these user groups and under what circumstances. The stimulus for the literature review presented in this paper is a Horizon 2020 funded project called ARCHES (Accessible Resources for Cultural Heritage EcoSystems) which involves museum education and technology partners across Europe [1]. The overarching aim of ARCHES is to create more inclusive cultural environments for adults who have a range of access preferences frequently associated with the labels of sensory impairments and learning disabilities [2]. One way in which the ARCHES project is attempting to achieve this aim is by

developing online resources, software applications and multisensory technologies to enable people with learning disabilities and sensory impairment to access museum learning opportunities. We are using participatory approaches to work collaboratively with over 100 participants from England (London), Spain (Madrid and Oviedo) and Austria (Vienna) along with 6 museums and 5 technology companies. Participants are taking a role in identifying existing useful technologies and resources that can promote inclusion; evaluating their experiences of activities and resources within museums; suggesting ways in which technologies might enhance their experiences or resources; evaluating test or beta-versions of technologies and analysing the processes and outcomes of the project as a whole. We felt that it may be helpful to conduct a literature review in order to examine whether there is a consensus in the field regarding how best to include users with learning disability and sensory impairments in the design process and what factors influence the decisions that designers and developers make regarding their design practices. It is our contention that such a review is needed because very little specific advice exists to guide interdisciplinary design teams about how best to include users with intellectual or sensory impairments in the process of designing technologies. In this paper we will begin by discussing what guidance currently exists to help designers decide whether to use these approaches with disabled users. We will then provide an overview of the method we used to undertake a literature review of studies that have involved users with learning disability or sensory impairments. We will then present the results of our review and discuss the extent to which analysis of the identified corpus of design literature enables us to distil out a decision-making framework for choosing appropriate design approaches when designing with users who have learning disability or sensory impairments. Finally, we will discuss what implications and recommendations can be drawn from the review that can inform the design practices of future design projects focusing on learning disability or sensory impairment.

2 Approaches to including users in the research and design of technologies

Common approaches to including users in the research and design of technologies are User-centred Design (UCD), Participatory Design (PD) and Human-Centred Design (HCD). Broadly speaking, these approaches offer designers a framework which requires them to address a number of issues or premises relating to: Who, What, When, How & Why (Giacomin, 2014). The ‘What’ relates to overarching focus or orientation of the approach (Ellis & Kurniawan, 2000; Blomberg & Henderson, 1990) and the underpinning values or principles (Ellis & Kurniawan, 2000; van der Bijl-Brouwer & Dorst, 2017). The ‘How’ relates to processes, tools and techniques [40]. The ‘Why’ relates to goals and motivations (Muller, Haslwanter & Dayton, 1997) (See Table 1). UCD, PD and HCD were not developed specifically with disabled users in mind. Some might argue that either Universal Design, Design for All, Accessible Design or Inclusive Design offer disability sensitive alternatives [Clarkson, 2003; Steinfeld & Maisel, 2012; Klironomos et al. 2006). However, we would argue that these offer design principles rather than design approaches and are therefore excluding consideration of them in our paper. We consider that these offer designers a framework of rules, guidelines or standards that they are encouraged to

comply with, they do not however elaborate on how exactly designers can enact these rules. Design approaches and associated techniques suggest specific actions, activities or processes. Consulting design principles may be an integral part of one or more of the stages within a design approach [see for example (See for example Huang & Chiu, 2016) but the principles are just one aspect of a design approach. With this distinction in mind, we have looked elsewhere for disability sensitive approaches to technology design.

Table 1: A comparison of design approaches against a framework of design factors

DESIGN FACTORS		**UCD**	**PD**	**HCD**
WHO	Who are the actors in the design process	End-users and designers/developers	Designers, end-users, external stakeholders	Users and other stakeholders, designers
	How are the end-users of the artefact being conceptualised	User as Informants (providing feedback) User as subject	User as Partner, active or full participant, co-designer	Humans Active
WHAT	Design orientation-key focus, overarching characteristic	Usability	Collaboration	Empathy Meaning-making
	Working principles or values underpinning design approach	Improving the understanding of user and task requirements	Democracy Interactive two-way relationship between designer and user	Gaining a clear understanding of users, how they interact with their environment and their needs, desires, experiences & perspectives,
WHEN	Early-late in the process	Early in the development cycle (but not necessarily in the initial idea stage) Throughout	Throughout	Throughout

	All or some stages in the process			
HOW	**Processes**	Iterative Design Empirical Measurement	Iterative	Reflective Evaluative Iterative
	Methods, Tools and techniques (that are unique to an approach or predominantly used)	Task analysis, needs analysis, Usability testing, heuristic evaluation, prototyping (lo-tech, rapid)	Ethnographic methods, Mock-ups, Games, role play, acting; Workshops; Diaries, scenarios	Consulting data-sets; ethnographic interviews and observations; focus groups, role-playing; think-aloud
WHY	Goals and/or motivations	A better (more usable) product	Better quality of life (through use of end-product) Better end-product	A better usable product Improved quality of life for users

2.1 Disability sensitive approaches to technology design

Some developers and researchers have offered alternative approaches to the standard UCD, PD and HCD approaches which they claim are more appropriate for working with disabled users. For example, Newell et al. (2011) argue that UCD methods provide little or no guidance about how to design for disabled people. They also argue that traditional UCD is problematic when the user groups include some disabled users or is entirely composed of disabled users. This means there is a greater variety of user characteristics and functionality which may mean it is difficult to find designs that suit disabled and non-disabled users or disabled users with different kinds of needs. They suggest an extension to UCD that they call 'User-Sensitive Inclusive Design' which they argue requires designers to develop a strong empathy with their disabled user groups. They reject standard UCD methods such as usability tests and experiments where users are positioned as 'subjects'. They propose alternative methods such as ethnography, personas, scenarios and theatrical techniques involving professional actors as useful and appropriate techniques to use with disabled users. Newell et al. do not however explain why they have not positioned their alternative as PD or HCD (or something else) but choose instead to remain within the UCD paradigm.

Bühler (2001) offers an alternative design approach for those developers who were aiming for the empowered participation of disabled users in technology-focused research and development projects. His framework, which he labels the 'FORTUNE concept' is underpinned by seven principles: partnership as a basis; users are

members of user organisations (so that they advocate on behalf of whole user group as well for themselves individually)the accessibility of all relevant materials and premises are guaranteed; every partner guarantees confidentiality, respect and expertise; there is a detailed plan for the project including time and resource planning for user participation and partnership is implemented from the beginning of the project. Buhler does not explicitly position this approach as an extension of PD, but there are some elements in common such as conceptualising the user as partner and involving the user in all stages of the design process. Reflecting on the potential practical and philosophical validity of the Fortune principles, our initial experience of working in the ARCHES project would suggest that it is important not to assume that members of a user group can effectively advocate for all members of the group. Some people can find it difficult to imagine how others in their group would respond and they may therefore need support to build this skill. We would also highlight that many disabled activists and researchers working in the field of critical disability studies would argue that empowerment for disabled people is not in the gift of non-disabled others, disabled people empower themselves by becoming agentic beings. Published in 2001, this approach appears to have had a limited influence on the field. A handful of studies that involve users with learning disability or sensory impairments have cited the FORTUNE concept as an example of a user participation framework or of PD, but they have not actually implemented it themselves (Saridaki & Mourlas, 2013; Kim et al. 2014; Millen et al. 2011).

2.2 Frameworks for choosing the most appropriate design approaches

Given the limited influence of proposed disability-sensitive extensions or alternatives to the standard design approaches it seems then that designers who are new to the field and intend working with users with learning disability or sensory impairments have little to help them decide which design approach might be the most appropriate or effective. An inspection of the main similarities and differences between UCD, PD and HCD as summarised in Table 1 provide no obvious indications as to why designers who wish to work with users who have learning disability or sensory impairments would choose one approach over another. The focus on democracy within the PD approach could be attractive to those working with people with learning disability and who are familiar with participatory or inclusive research frameworks because of their emphasis on equal partnerships between participant and researcher and their positioning of people with learning disability as co-researchers.

Interestingly, drawing on participatory research literature, Draffan et al. (2016) propose a framework to enable assistive technology designers to decide the level of participation that disabled users will be afforded with each design project (from non-involvement through to participant initiated and directed). Their framework requires designers to consider the potential strengths of the user, the tasks required of the user, the resources required to enable participation (e.g. training) plus the expertise users bring with them, the environment in which they may be working and the tools they may need to support participation (e.g. communication aids). They argue that “careful analysis of all the components involved in the suggested framework can lead to better AT participatory design and research methodologies with potential users informing

best practice". Whilst this framework might be helpful to PD designers, it does not help designers choose between UCD, PD and HCD, nor suggest any disability-specific adaptations of PD methods. However what this framework does offer is some series of questions (which may need to be extended further to generalise to UCD and HCD design projects) that designers can ask themselves in order to increase the chances of the employment of the design approach being successful. Questions relating to the user, what they will be asked to do, the environment in which they will be asked to design and the resources and time available to support participation in the design process.

Given the lack of broad frameworks that cover all three main design approaches we would argue that it is important to interrogate the research and development literature in more detail in order to examine how designers decide which design approach to use with users who have learning disabilities or sensory impairments; what factors influence their choices and the extent to which the approaches adopted as a result are successful. In the following section we will outline the method we used to undertake such a review and to answer the following questions:

1. What design approaches are commonly used to include users with learning disability or sensory impairments in the design of technologies?
    a. What factors influence the choice of design approach?
    b. What justifications are given for the choices of design approach
    c. What factors influence the successful employment of the chosen design approach?
    d. What evaluative evidence is provided to demonstrate successful employment of the design approach with the intended user group?

3 Review Method

The literature review took place between October 2016 and March 2018. The SCOPUS database was searched as it includes a range of journals that reflect the multidisciplinary nature of research in the field of learning disability and technology design. In addition Scopus is the worlds' largest abstract and citation database of peer-reviewed literature containing 36,377 titles from approximately 11,678 publishers, of which 34,346 are peer-reviewed journals. A particular focus of the search was the design of technologies similar to those being developed within the ARCHES project. A range of keyword terms were used to search for outputs related to learning disability and sensory impairment in order to reflect the national and disciplinary differences in labels used to categorise this group of people. The parameters of the review include: the date range of the search was restricted to the last twelve years in anticipation that design approaches may be quite different for older technologies designed and evaluated prior to 2006; included where users with either learning disability or sensory impairments were included in the design process. Papers were excluded if the users were children below the age of eighteen or if the majority of the user group were classed autistic (which we are not defining as being as example of learning disability, but we recognise that some authors do). Our search produced 59 papers. A two-level filtering process reduced the number of papers down to a corpus

of 32 (See Table 2). Once the 32 papers had been identified, they were each re-read and notes were made on anything within the paper that had implications for approaches to technology design. In the following sections we will provide an overview of the corpus of the 32 papers then present our analysis of the decisions and evaluations made regarding design approaches.

4 Overview of the corpus of papers

In presenting the results of our literature review we will begin by providing an overview of the corpus of papers found in our search in order to provide a detailed context for the review findings; particularly in relation to access needs, age range, technologies and intended purpose of technology use .18 papers involved users with sensory impairments as their primary user group. Of these, three involved blind users (Feng, 2016; Sahib et al. 2013; Tixier et al. 2013); Seven involved visually impaired users, three involved both blind and visually impaired users (Azenkot et al. 2016; Batterman et al. 2018; Dietz et al. 2016); two involved deaf users (Rocha et al. 2017; Smith & Nolan, 2016); two involved deaf or hard of hearing users (Kawas et al. 2016; Peruma & El-Glaly, 2017) and one involved hard of hearing users (Ferreira & Bonacin, 2013). 14 papers involved users with learning disability as their primary user group. Two papers involved users with both intellectual and sensory impairment (Brown et al. 2011; Hassell et al. 2012) and one paper also included users with complex communication needs (Prior, 2010). None of the papers reported working solely with middle aged or older adults. The technologies being designed in the 32 papers were diverse and included haptic devices, games, robots, avatars, websites, interfaces and mobile applications. 18 papers reported focusing on designing new technologies. For example, one study worked with eight blind participants to create wearable controls for mobile devices (Feng, 2015). The design of the technology was based on previous studies that should how hazardous it is for blind users to listen to their phone's guiding instructions whilst trying to move around the urban landscape. 15 papers reported focusing on re-designing existing technologies. For example one study involving users with sensory impairments focused on designing a tactile button interface that could control the native Voice-Over Gesture navigations of IOS devices (Batterman et al. 2018). There were nine intended purposes of the technologies that the projects were developing: communication, daily living, education, employment, health, accessing information, leisure, safety and travel. It is noticeable that the projects that focused on education involved just users with sensory impairments (Batterman et al. 2018; Huang & Chiu, 2016; Peruma & El-Glaly (2017). The projects that ocused on health involved just users with learning disability (Buzzi et al. 2016; Prior 2010). The average size of the user group was 11 (range 1 to 48).

5 Design approaches commonly employed with users who have learning disability or sensory impairments

When making decisions about how to categorise the design approach of each paper, we took into account any explicit claims the author made in the title, keywords, abstract or main body of the paper. Where there was no explicit statement about the

approach we used our professional judgment based on the nature of the design papers they cited in support of their work and/or how closely they fitted to the design characteristics outlined in Table 1.

Table 1: The corpus of papers included in the review

Azenkot, S., Feng, C., & Cakmak, M. (2016). Enabling building service robots to guide blind people: A participatory design approach. In *Proceedings of ACM/IEEE International Conference on Human-Robot Interaction*, HRI 2016, (pp 3-10) (Christchurch, New Zealand)
Batterman J.M., Martin, V.F., Yeung, D., & Walker, B.N (2018). Connected cane: Tactile button input for controlling gestures of iOS voiceover embedded in a white cane. *Assistive Technology,* 30, 91-99.
Chan, M.K., & Siu, K.W.M. (2013). Inclusivity: A study of Hong Kong museum environments. *International Journal of Critical Cultural Studies,* 11, 45-61
Dietz, M., Garf, M.E., Damian. I., & André, E. (2016). Exploring eye-tracking-driven sonification for the visually impaired. In *Proceedings of the 7th Augmented Human International Conference*, AH16, (Article No 5) (Geneva, Switzerland).
Feng, C. (2016). Designing wearable mobile device controllers for blind people: A co-design approach. In *Proceedings of the 18th International ACM SIGACCESS Conference on Computers and Accessibility*, ASSETS 2016 (pp 41-342) (Reno, USA).
Ferreira, M.A.M., & Bonacin, R. (2013). Analyzing barriers for people with hearing loss on the web: A semiotic study. In *Proceedings of International Conference on Universal Access in Human-Computer Interaction,* UAHCI, (pp 694-703) (Las Vegas, USA).
Huang, P-H., Chiu, M-C. (2016). Integrating user centered design, universal design and goal, operation, method and selection rules to improve the usability of DAISY player for persons with visual impairments. *Applied Ergonomics,* 52, 29-42.
Kawas, S., Karalis, G., Wen, T., & Ladner, R.E. (2016). Improving real-time captioning experiences for deaf and hard of hearing students. In *Proceedings of the 18th International ACM SIGACCESS Conference on Computers and Accessibility*, ASSETS 2016 (pp 15-23) (Reno, USA)
Kim, H.N., Smith-Jackson, T.L., & Kleiner, B.M (2014). Accessible haptic user interface design approach for users with visual impairments. *Universal Access in the Information Society*, 13, 415-437.
Mi, N., Cavuoto, L.A., Benson, K., Smith-Jackson. T., & Nussbaum, M.A. (2014.) A heuristic checklist for an accessible smartphone interface design. *Universal Access in the Information Society,* 13, 351-365.
Parkinson, A., & Tanaka, A. (2016). The Haptic Wave: A device for feeling sound. In *Proceedings of Conference on Human Factors in Computing Systems*, CHI 2016, (pp 3750-3753) (San Jose, USA).

Peruma, A., & El-Glaly, Y.N. (2017). CollabAll: Inclusive discussion support system for deaf and hearing students. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*, ASSETS 2017, (pp 315-316) (New York, USA).

Rocha, T., Paredes, H., Soares, D., Fonseca, B., & Barroso, J. (2017). MyCarMobile: A travel assistance emergency mobile app for deaf people. In *Proceedings of IFIP Conference on Human Computer Interaction*, INTERACT 2017, (pp 56-65) (Mumbai, India).

Sahib, N.G., Stockman, T., Tombros, A., & Metatla, O. (2013). Participatory design with blind users: A scenario-based approach. In *Proceedings of IFIP Conference on Human Computer Interaction*, INTERACT 2013, (pp 685-701) (Cape Town, South Africa).

Smith, R.G., & Nolan, B. (2016). Emotional facial expressions in synthesised sign language avatars: a manual evaluation. *Universal Access in the Information Society* 15, 567-576.

Tanaka, A., & Parkinson, A. (2016). Haptic wave: A cross-modal interface for visually impaired audio producers. In *Proceedings of Conference on Human Factors in Computing Systems*, CHI 2016, (pp 2150-2161) (San Jose, USA).

Tixier, M., Lenay, C., Le Bihan, G., Gapenne, O., & Aubert D. (2013). Designing interactive content with blind users for a perceptual supplementation system. In *Proceedings of the 7th International Conference on Tangible, Embedded and Embodied Interaction*, (pp 229-236). (Barcelona, Spain).

Yuan, C.W., Hanrahan, B.V., Lee, S., Rosson, M.B., & Carroll, J.M. (2017) Constructing a holistic view of shopping with people with visual impairment: a participatory design approach. *Universal Access in the Information Society*, 18, 1-14.

Allen, K., Hollinworth, N., Minnion, A., Kwiatkowska, G., Lowe, T., Weldin, N., & Hwang, F. (2013). Interactive sensory objects for improving access to heritage. In *Proceedings of Conference on Human Factors in Computing Systems*, CHI, 2013, (pp 2899-2902) (Paris, France).

Brown, D.J., McHugh, D., Standen, P., Evett, L., Shopland, N., & Battersby, S. (2011). Designing location-based learning experiences for people with intellectual disabilities and additional sensory impairments. *Computers and Education* 56, 11-20.

Buzzi, M.C., Buzzi, M., Perrone, E., Rapisarda, B., & Senette C. (2016). Learning games for the cognitively impaired people. In *Proceedings of 13th Web for All Conference*, W4A 2016. (Article no 14) (Montreal, Canada).

da Silva, D.M.A., Berkenbrock, G.R., & Berkenbrock, C.D.M. (2017). An approach using the design science research for the development of a collaborative assistive system. In *Proceedings of CYTED-RITOS International Workshop on Groupware*, CRIWG 2017, (pp 180-195). (Saskatoon, Canada)

Dekelver, J., Daems, J., Solberg, S., Bosch, N., Van De Perre, L., & De Vliegher, A. (2015). Viamigo: A digital travel assistant for people with intellectual disabilities: Modelling and design using contemporary intelligent technologies as a support for independent traveling of people with intellectual

disabilities. In *Proceedings of 6th International Conference on Information, Intelligence, Systems and Applications*, IISA 2015, (art. no. 7388014). (Corfu, Greece).
Hassell, J., James, A., Wright, M., Litterick, I. (2012). Signing recognition and cloud bring advances for inclusion. *Journal of Assistive Technologies* 6, 152–157.
Hollinworth, N., Allen, K., Kwiatkowska, G., Minnion, A., & Hwang, F. (2014). Interactive sensory objects for and by people with learning disabilities. *SIGACCESS Newsletter* 109, 11-20.
Hollinworth, N., Allen, K., Hwang, F., Minnion, A., & Kwiatkowska, G. (2016). Interactive sensory objects for and by people with learning disabilities. *International Journal of the Inclusive Museum* 9, 21-38.
Hooper, C.J., Nind, M., Parsons, S., Power, A., & Collis, A. (2015). Building a social machine: Co-designing a TimeBank for inclusive research. In: *Proceedings of the 2015 ACM Web Science Conference*. (Article Number 16) (Oxford, United Kingdom).
Iversen, O.S., & Leong, T.W. (2012). Values-led participatory design - Mediating the emergence of values. In *Proceedings of the 7th Nordic Conference on Human-Computer Interaction*, NordiCHI 2012, (pp 468-477). (Copenhagen, Denmark).
Prior, S. (2010.) HCI methods for including adults with disabilities in the design of CHAMPION. In *Proceedings of Conference on Human Factors in Computing Systems*, CHI, 2010, (pp 2891-2894). (Atlanta, USA).
Usoro, I., Connolly, T., Raman, S., French, T., & Caulfield, S. (2016). Using games based learning to support young people with learning disabilities stay safe online. In *Proceedings of the European Conference on Games-based Learning*, (pp 704-712) (Paisley, Scotland).
Wilson, C., Sitbon, L., Brereton, M., Johnson, D. & Koplick, S. (2016). 'Put yourself in the picture': Designing for futures with young adults with intellectual disability. In *Proceedings of the 28th Australian Computer-Human Interaction Conference*, OzCHI 2016, (pp 271-281). (Launceston, Australia).
Xu, Y., Zhang, J., Yagovkin, R., Maniero, S., Wangchunk, P., & Koplick, S. (2014). Rove n Rave™ development: A partnership between the university and the disability service provider to build a social website for people with an intellectual disability. In *Proceedings of the 26th Australian Computer-Human Interaction Conference*, OzCHI 2014, (pp 531-534). (Sydney, Australia).

Our analysis revealed that two studies adopted HCD approaches; six used UCD, 12 employed PD approaches (including two that used co-design) and eight adopted a hybrid approach. Four papers adopted approaches other than UCD, PD, HCD or hybrid. Overall there was a clear preference for using PD and hybrid approaches with users with sensory impairments whilst approaches employed with users with learning disability was much more eclectic. In order to try and understand this pattern of adopted design approaches we will next examine the justifications that designers gave for their choice of design approach and whether these were specifically linked to the difficulties and difficulties experienced by the intended user group.

5.1 Justifications for the choice of design approach

There was a huge variation across the corpus regarding whether or not a justification was offered for the choice of approach, and the extent to which those justifications proffered were supported by evidence such as citing broad design literature or specific studies that have also employed the approach.

User-centred design

Two of the papers offered no definition of UCD or justification as to why UCD might be an appropriate approach to employ with the user group (Smith & Nolan, 2016; Hassell et al. 2012). One paper did not offer a definition of UCD, but did cite the ISO standard for UCD. However, they did not engage in any justifying of the approach or make it clear how the approach they adopted with deaf participants mirrored the approach advocated by the ISO (Rocha et al. 2017). In a brief conference paper focusing on the design of hospital patient profiling software for people with complex communication needs and cognitive impairment, the researchers offered no definition of UCD but did state that little UCD work has been done with adults with complex communication needs who may also have cognitive impairments (Prior, 2010).

One project analysed the strengths and weaknesses of the UCD approach and argued that although it can better address the user needs and preferences it cannot analyse the user requirements and product function in detail, therefore requiring the involvement of additional usability experts (Huang & Chiu, 2016). In order to address the weakness of UCD therefore, they integrated the use of Universal Design principles and the GOMS (Goals, Operators, Methods and Selection) model into their approach. Whilst this SWOT analysis provides a rationale for the integration of UD and GOMS it does not provide a rationale as to why UCD is appropriate to use with visually impaired users or discuss the potential cons of using techniques such as UD and GOMS which do not require user involvement.

Hooper et al. (2015) describe a project in which they sought to design an online social platform that would facilitate inclusive research partnerships with people with learning disability. The title of their paper includes reference to ‘co-design’. Despite this they do not position the methods they used to design the platform as inclusive research methods, or PD, but rather UCD. They draw on a range of UCD studies and publications to position their work including Gould and Lewis (1985). They define UCD as involving:’ the user of a product or service through all the stages of the design of that product or service’. Continuing their rather ‘fluid positioning, Hooper et al. justify their use of UCD by arguing that it will result in more appropriate, acceptable designs. They also acknowledge that trying to support the ‘more equitable involvement if users in pursuing this goal’ is not without tensions and challenges.

Participatory Design

Eight papers offer no definition of their PD approach or if they did, they offered no rationale for why they were using it with their user groups beyond rather vague implications that PD enables user needs to be met (see for example Ferreira and Bonacin, 2013:p696). Just five papers offered some rationale. For example, Azenkot et al. (2016) sought to design specifications that detail how a building service robot could interact with and guide a blind person through a building in an effective and socially acceptable way. Drawing on the work of Kensing and Blomberg (1998) and Sanders et al. (2010) they define PD as: 'a method where a system is designed collaboratively by designers and target users". Their rationale for using PD appears to centre on the fact that PD has been used before with disabled people, although the one reference they cite in support of this, was for a project involving users with aphasia rather than blind people. Kim et al. (2014) have an explicit rationale for using PD with their disabled user group arguing that 'users with disabilities have specific needs and requirements for assistive technology applications that are hardly expected by designers without disabilities; thus, they should be involved throughout the entire design process'. They also refer to the fact that the PD approach has been shown appropriate and effective for people with disabilities. They cite the work of Wu et al. (2005) who used PD to design an orientation aid for amnesiacs and Wattenberg (2005) who described the use of focus groups as an 'accessible research method' with visually impaired people. Tixier et al. (2013) justify the use of PD in general terms, rather than relating to specifically to why it is appropriate for use with disabled people. They do however, state that few studies have focused on the use of PD in this field. In referring to the lack of studies, Tixier et al. do cite three papers, one that has used PD with users with learning disability and two that have used PD with users with visual impairment. Sahib et al. (2013) justify their use of PD with blind users, because they argue it is hard for sighted users to design for non-sighted users. We also note that none of these papers made reference to Bühler's FORTUNE design framework.

Human-centred design

Chan & Siu (2013) cite just one HCD reference (the out of date ISO 1999 international standard for HCD processes) and they don't justify the use of HCD per se, but rather their use of 'user needs analysis. Furthermore, their justification refers broadly to issues of diversity, rather than visual impairment. Dekelver et al. (2015) do not explicitly define HCD, but they indicate that there is a scarcity of literature documenting the use of a human-centred approach with people with learning disability. Dekelver et al. do argue that a human-centred approach is an appropriate one to use because 'design must support the easiness of use'. But they do not make it clear why HCD would support easiness of use over and above other approaches such as UCD or PD.

Hybrid approaches

Eight papers adopted a hybrid approach- combining two design approaches. Not all of them explicitly claimed that their approach was hybrid in nature, but when we interrogated their description and matched against the characteristics outlined in Table 1 we concluded that there were elements of two approaches. Five papers combined PD with UCD (Dietz et al. 2016; Mi et al. 2014; Parkinson & Tanaka, 2016; Tanaka & Parkinson, 2016; da Silva et al. 2017) and three papers combined PD with HCD (Kawas et al. 2016; Yuan et al. 2017; Wilson et al. 2016). It is interesting to note that no studies combined UCD with HCD. Mi et al. (2014) describe a three phase project which was largely UCD in nature. The first phase involved a comprehensive review of existing standards, guidelines and user requirements regarding mobile handheld device accessibility. The second phase included both heuristic evaluation and usability testing. The third phase configured the finalized design guidelines into a heuristic checklist for designing accessible smartphones, which could be generalized and applied to other mobile or touchscreen-based devices. However, in the first phase, the designers used PD to filter a set of preliminary user requirements. Da Silva et al. (2017) positioned their methodology as Design Science Research consisting of two 'steps': UCD and PD. The first step used UCD to identify the system requirements which resulted in prototypes of augmentative communication screens. The second step employed the PD approach to enable users to choose the screens images and evaluate the system usability.

Three of the eight studies offered no definition, no references and no rationale for either the hybrid approach or why the hybrid approach might be appropriate to use with their disabled users (Dietz et al. 2016; Parkinson & Tanaka, 2016; Tanaka & Parkinson, 2016). Five studies offer some limited (typically implicit rather than explicit) rationale for adopting a hybrid approach- but not for why it would be appropriate with disabled users (Huang & Chiu, 2016; Kawas et al. 2016; Mi et al. 2014; da Silva et al. 2017; Wilson et al. 2016). For example, Kawas et al. (2016) talk about the need for a 'holistic qualitative approach' view. They do not however explicitly claim that their hybrid approach of HCD and PD would enable this or why such an approach is needed with users with sensory impairment. Furthermore, none of their 26 references relate to methods, instead they are all related to Automatic Speech Recognition and captioning for deaf and hard of hearing people, which rather weakens any argument they are making about the validity or appropriateness of the method. Yuan et al. (2017) employed what in our view was a combination of PD and HCD. However their rationale for why their approach is appropriate to use with users who are visually impaired, focus more on the PD component than the HCD component. They argue: 'Such a PD process allows us to observe PVI's practices from a holistic perspective and to develop trust, which also benefits from a long-term engagement before we introduce design changes into these practices.' Yuan et al. do however cite a range of studies as support for their approach, including generic design papers (e.g. Carroll et al. 2000) and those specifically describing design approaches with visually impaired users (e.g. Katz et al. 2012).

Approaches other than UCD, PD, HCD or hybrid

Four papers reported using an approach other than UCD, PD, HCD or hybrid (Allen et al. 2013; Brown et al. 2011; Hollinworth et al. 2014, 2016). All of them involved users with learning disability and adapted their approach in some way to cater for their needs (all except paper 20 do not specify how many users they involved). The only clue to how Brown et al. (2011) are positioning the design of their project is in a section heading title "User sensitive design'. However in the text within the section Brown et al. do not define user sensitive design, nor do they cite the work of Newell et al. (2011) regarding user sensitive design**.** Apart from occasionally using the language of inclusion with terms such as 'co-discovery', there is no other referral to the inclusive design literature or discourse. Three papers, all reporting on the same project (Sensory Objects Project) position their approach as inclusive research (Allen et al. 2013; Hollinworth et al, 2014, 2016).

The researchers actually use the term 'inclusive design' to describe their approach, however the reference to researchers and co-researchers along with reference to the work of well-known participatory/inclusive research studies would suggest that they are sympathetic to inclusive research and perhaps see no difference between inclusive design and inclusive research (Walmsley & Johnson, 2003). This conflation of the two terms inclusive research and inclusive design may also reflect the multi-stakeholder nature of the project team.

5.2 Evaluations of choice of approach

Across the corpus, just eleven papers offered some evaluative reflections or comments on the perceived success or failure of their chosen design approach with the intended user group. These were spread evenly across the user groups (6 sensory impairment projects and 5 learning disability projects). Interestingly, there were no evaluations from studies that had employed UCD. Evaluations focused on seven areas: user needs, skills and difficulties; the experience of the process for the user, the quality of the end-design or product; the pragmatics of conducting the study; stakeholder needs and values and researcher skills, needs or difficulties.

User related evaluations

Chan & Siu (2013) argue that the iterative nature of the study enabled them to design a system based on the needs of visually impaired people. This is however the extent of their evaluation of how successful or appropriate the use of HCD with their users group was. Sahib et al. (2013) provide a bit more information as to why involving blind users at an early stage allowed them to identify limitations with their own design ideas. They share how 'participants would often question the practicality of the proposed interface features, requiring detailed explanations of how these interface components would be accessed in a realistically usable way with screen readers'. Similarly Xu et al. (2014) report: 'Without working with people with an intellectual disability, the team may not have realised how subtle changes to colour, icons, pictures and wording would have a large effect on how people with an intellectual disability understand and use Rove n Rave'. However they also report that the biggest challenge for their team was the fact that users had such different reactions to one

another despite all having the same ‘label’. Allen et al. (2013) conclude that they have learnt not to underestimate their co-researchers interest and ability to use technology.

Design process

Two studies that involved users with sensory impairments offered specific recommendations to other designers regarding the design process. One study that employed PD recommended that researchers introduce participants to the design at the early stages of the process, to spur creativity while providing some necessary constraints (Azenkot et al. 2016). Another study that used PD made three recommendations. Firstly, to ‘consider the whole process of an activity in design so as to identify actual needs and possible technology supports that take place at each stage and as a whole’. Secondly to shift the design focus away from steps (e.g. identify an item) towards activities (e.g. organising the pantry). Thirdly, to not get distracted and consumed by the ‘mitigating deficits’ of the users (Yuan et al. 2017).

Experience of the process for the user

Three studies report on the influence of their approach on the engagement and motivation levels of their users. Hollinworth et al. (2016) comment positively on the impact of using inclusive research methods with users with learning disability. They noted that their co-researchers were so highly engaged to the extent that they were keen to share the project with their peers. They also suggest that they experienced an increase in confidence and empowerment, but present no explicit evidence for this claim. Usoro et al. (2016) claim that the use of a PD approach with young people with learning disability enhanced user engagement throughout the process. Working with people with visual impairment, Yuan et al. (2017) claim that their hybrid of HCD and PD and in particular their detailed attention to shopping practices of the users led the users to trust the design team. They also comment on a growing willingness of the users to stand-up and testify about the project to external stakeholders.

Researcher skills, needs or difficulties

Two projects reflected on their experiences regarding the nature and the level of skills that researchers require in order to successfully engage in design projects with people with learning disability. Dekelver et al. (2015) conclude that using HCD with intellectually impaired users requires sociological skills in order to fully understand the specific position of people with learning disability at home and in care and work placement centres. Allen et al. (2013) conclude that they have learnt the importance of using all their senses in the development of museum interpretation in order to give more chance of engagement to people with different disabilities and interests.

Product related

Two PD projects claim that using this approach resulted in working, usable technology (Batterman et al. 2018; Buzzi et al. 2016). For example Buzzi et al. claim that allowing PD to drive the development of their learning platform resulted in

feedback that led to making the games customizable in terms of discriminative stimuli, difficulty levels and reinforcement, as well as the creation of a game "engine" to easily set up new personalized exercises. They claim that these customization features not only meet the needs of the users, but broaden the appeal of the platform to a wider user group.

Study pragmatics

Mi et al. (2014) conclude that one of the greatest challenges in conducting research with users with impairments is access to the participants themselves. An additional limitation they identified is the variability in the time each PD member spent learning how to use the prototype prior to evaluation. They argue that 'factors such as work schedules and insufficient learning assistance may be potential threats to the study control, but also other factors, such as frustration with the new technology, may have negatively affected interest in phone exploration'. We would suggest however that this problematizing of the user and not the technology is unhelpful and potentially inappropriate. We are unconvinced that a well-designed product would require a user to invest significant time to learn how to use it. Furthermore, from our own experience, disabled people can be reluctant to take part in studies due to negative prior experiences, particularly if they felt that their participation was tokenistic and not taken seriously.

Another study involving users with sensory impairments that lasted for about a year also concluded that it was important to engage in PD for an extended period of time and that short-term engagements 'may not be sufficient for the designers to fully grasp users' needs and practices' (Yuan et al. 2017). However, they do not specify how they would define short-term engagement. Interestingly, an analysis of the duration of each of the studies in the corpus reveals that the duration of a study ranged from 1 day to 1095 days and the average (mean) duration for a study was longer for those involving users with learning disability (412 days) compared to those involving users with sensory impairments (320 days). When comparing average (mean) duration by approach, the shortest was UCD (26), followed by HCD (117 days), PD (122 days), Hybrid (488 days) and Other (1095 days). The figures for HCD probably does not reflect reality, given that HCD methods are meant to involve ethnographic studies of users' lives and experiences. However, we suspect the high figure for Hybrid studies reflects the fact that half of these studies included HCD as part of the 'mix'.

Stakeholder needs or values

Allen et al. report that the Visitor Experience Officer at the heritage site noted that the Sensory Objects workshop consultation process was important to the owners of site who wanted to make their exhibits more credible. It also fitted with their organisational philosophy.

6 Discussion

In the previous two sections we have analysed the studies in our corpus with respect to the decisions and evaluations made regarding the design approaches employed with users with learning disability or sensory impairment. In this section we will summarise our findings by highlighting the common factors that appear to influence design decisions and the common issues raised when evaluating the success of design projects.

Our review reveals that UCD, PD and HCD were all employed within the corpus, but that PD was the most commonly used and HCD was the least commonly used. Given that HCD is quite a labour intensive method requiring a range of both computer science and social science skills (Dekelver et al. 2015) it is perhaps understandable why it might be the least used approach. On the other hand given that many of the intended purposes of the technologies being designed were to support disabled users undertake tasks and activities within their own environment (e.g. travel, leisure, employment and daily living skills such as shopping) and that HCD is a method that involves understanding how users interact with their environment it could also be surprising that more studies did not employ HCD.

6.1 Factors that might influence the choice of design approach

When considering the factors that might influence the choice of design approach we noted that PD was more commonly used with users with sensory impairments and that the choice of approach was more varied for studies involving users with learning disability. One reason why PD is more common approach to use might be that some designers may assume that people with learning disability do not have the mental capacity to engage in co-design activities. This needs further investigation however, and it is important to remember one of the conclusions from a study that did involve users with learning disability regarding not under-estimating the interest and ability of people with learning disability to use technology (Allen et al. 2013). From our personal knowledge of the design teams, we would also like to highlight that those studies where approaches other than UCD, PD and HCD had been adopted with users with learning disability involved experienced multidisciplinary teams that had years of experience of involving people with learning disability, which perhaps gave them the knowledge and the confidence to find other creative design approaches (Allen et al. 2013; Brown et al. 2011; Hollinworth et al, 2014, 2016).

There was a huge variation across the corpus regarding whether or not a justification was offered for the choice of approach, whether the justification was related to the disabilities of the user groups and the extent to which those justifications proffered were supported by evidence. This makes it hard to discern whether there were any valid reasons for choosing one design approach over another when working with users with learning disability or sensory impairments. The tendency not to offer definitions of the approach being used made it difficult on many occasions to ascertain the overarching design orientation or the principles and values that the designers were using to underpin their design decisions. The tendency not to cite other studies that have been conducted with users with learning disability or sensory impairments could be argued to be due to a lack of studies in this area as

some of the authors suggest (Tixier et al. 2013; Dekelver et al. 2015; Prior, 2010). Choosing to cite studies that did not involve users with intellectual or sensory impairments but did involve users with other impairments in order to support design choices (Kim et al. 2014) may suggest that designers assume that disabled people are a homogenous group and that there is no need to consider their specific abilities and needs when considering which design approach to use.

6.2 Factors that designers may need to take into account in order to effectively employ a particular approach

When considering the factors that designers may need to be taken into account in order to effectively employ a particular approach we noted that UCD studies were on average the shortest in duration and that 'Other' design approaches (which typically involved employing elements of inclusive research, working with people with learning disability in particular) were the longest (See Table 5). It is also interesting to note that for most of the design approaches, the age of the user does not appear to be important, since it was most common for researchers not to report their age in their papers. Age was reported more commonly in the PD studies and a possible trend was observed in that more studies involved young adults than the other age groups. This may be because there was an assumption that younger adults are more frequent technology users and therefore could give more informed responses regarding the strengths and weaknesses of new technology designs. Similarly, if we ignore the potentially distorted figures for HCD and 'Other', there is not a lot of difference between the average size of groups across the design approaches.

The lack of a comprehensive or detailed evaluation of the success or the failure of the chosen approaches with users with learning disability or sensory impairments makes it difficult to draw any confident conclusions regarding what factors influence the successful employment of a design approach with users with learning disability and sensory impairments. This lack of evaluation, particularly of any failures or weaknesses in the employment of their approach may be symptomatic of the researchers desire to show their work and product in a positive light in order to secure future funding. What little evaluation evidence we have identified suggests that:

- involving people with learning disability and sensory impairments in PD and HCD results in usable technologies (Batterman et al. 2018; Chan & Siu, 2013; Buzzi et al. 2016);
- using PD, hybrid and 'other' approaches with users with learning disability and sensory impairments can lead to high levels of engagement and commitment (Yuan et al. 2017; Hollinworth et al. 2016; Usoro et al. 2016);
- designers working with users with learning disability learn a lot about themselves and the needs of people with learning disability and sensory impairments when they adopt PD, HCD or 'Other' approaches to design (Allen et al. 2013; da Silva et al. 2017; Xu et al. 2014).

We do however need far more evidence to support these tentative conclusions; which requires future studies in this area to be far more evaluative than those in our corpus have been.

7 Conclusion

With regards to identifying a decision-making framework for deciding between design approaches our literature review has not revealed a clear framework. For example, whilst we noticed a pattern in favour of using PD with users with sensory impairments the lack of evidence-based justifications for this or detailed evaluations of the success of the approach means that there is no clear reason behind such a decision. We would recommend therefore that future studies, irrespective of which approach they are employing make their decision-making process much more explicit and detailed. Our review of the literature have revealed significant variation in the approaches used by designers and researchers along with large variation regarding whether or not a justification for the choice of design approach is offered. Where a justification is offered, there is huge variation in whether that justification is related to the needs of the intended user group or supported by evidence. In addition there is a lack of comprehensive and detailed evaluation of the design approaches employed within the corpus studies. Technology designers (and their partners from other disciplines) who are new to the field and intend working with users with intellectual or sensory impairments therefore currently have little to help them decide which design approach might be the most appropriate or effective. It is our contention that the value and effectiveness of future technologies will be severely limited unless more work is done to articulate and justify a meaningful decision-making framework.

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9 Notes

[1] https://www.arches-project.eu/

[2] At the outset of the project a broad label was proposed: “People who experience differences and difficulties associated with perception, memory, cognition and communication”. As the project progressed however, it became clear that not all the participants wished to be defined by this or any other label. There was a collective agreement therefore to subsequently refer to participants as having access preferences.

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